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# Definitions of Quality of Life: What Has Happened and How to Move On

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**Background:** Quality of life (QOL) is an important outcome in spinal cord injury (SCI) rehabilitation, but it is unclear how to define and measure it. **Objective:** The aims of this article are to (a) show how the concepts of QOL and health-related quality of life (HRQOL) have evolved over time, (b) describe the various ways QOL has been defined and measured, and (c) provide recommendations on how to be as clear and consistent as possible in QOL research. **Method:** A narrative review of the QOL literature was performed. **Results:** Roots of the term “quality of life” in health care can be traced back to the definition of health by the World Health Organization in 1948. The use of the word “well-being” in this definition is probably a main factor in the continuing confusion about the conceptualization of QOL. Within the field of SCI rehabilitation, the Dijkers’s QOL model, distinguishing between utilities, achievements, and subjective evaluations and reactions, has been very influential and the basis for several reviews and databases. Nevertheless, literature shows that it is still difficult to consistently use the term “quality of life” and categorize QOL measures. Several aspects of QOL that are specific for individuals with SCI have been identified. **Conclusions:** Researchers should be as specific and clear as possible about the concept and operationalization of QOL in their studies. Readers should not take the term “quality of life” for granted, but should inspect the topic of the study from the actual measures used. **Key words:** health status, outcome assessment, quality of life, spinal cord injuries

## Introduction

Because of improvements in medical care, the average life expectancy of people with spinal cord injury (SCI) has increased considerably in recent decades.<sup>1</sup> However, SCI still is a major life event that leads to serious physical disability and a large number of secondary health conditions (SHCs), the most frequent being pain, bowel and bladder regulation problems, muscle spasms, fatigue, heart burn, and osteoporosis.<sup>2</sup> Research clearly shows an overall negative impact of SCI on labor market participation, leisure activities, and social relations<sup>3</sup>; an elevated prevalence of depression, anxiety, and posttraumatic stress disorder (PTSD) compared to the general population<sup>4</sup>; and on average substantially lower life satisfaction compared to the general population.<sup>5</sup>

Due to the wide range of consequences of SCI, it is clear that outcome measures covering basic activities of daily living such as the Functional Independence Measure<sup>6</sup> or the Spinal Cord Independence Measure<sup>7</sup> are insufficient to capture the complexities of living with SCI and

thereby to measure rehabilitation outcomes after SCI.<sup>8,9</sup> Many agree that quality of life (QOL) should be measured in tandem with traditional outcomes assessing functional rehabilitation, because such measurements provide different yet complimentary information that aids clinicians in their efforts to help those with SCI.<sup>10,11</sup>

There is a wealth of data on QOL of individuals with SCI. A PubMed search (May 4, 2014) revealed more than 1,000 hits using the combination of the search terms “spinal cord injury” and “quality of life.” The interpretation of the results of these studies is severely limited by the general lack of consensus on how to define and measure QOL.<sup>11</sup> Consequently, our understanding of QOL among individuals with SCI is still limited. Authors have pled for consensus on a concrete, universal definition of QOL.<sup>11</sup> However, such a consensus among researchers and clinicians across diagnostic groups is unlikely to emerge in the near future. Nevertheless, we should do our best to minimize the confusion and to learn as much as possible from the QOL studies that have been and are being performed. The aims of this article are therefore

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to (a) show how the concepts of QOL and health-related quality of life (HRQOL) have evolved over time, (b) describe the various ways QOL has been defined and measured, and (c) provide recommendations on how to be as clear and consistent as possible in QOL research.

### QOL in Medicine

Since its introduction in the medical literature in the 1960s, the term “quality of life” has become increasingly popular in recent decades. In 1975, quality of life was introduced as a key word in medical literature databases. A PubMed search for studies with quality of life in the title retrieved only 0 to 1 articles/year in the 1960s, but this number has grown to almost 4,000 references in 2013 alone (search performed on May 4, 2014).

One of the earliest publications on QOL is an editorial in the *Annals of Internal Medicine*.<sup>12</sup> In this editorial, Elkington addressed the new ethical issues associated with the increase of treatment success with sometimes adverse effects for the patients involved:

What every physician wants for every one of his patients old or young, is not just the absence of death but life with a vibrant quality that we associate with a vigorous youth. This is nothing less than a humanistic biology that is concerned, not with material mechanisms alone, but with the wholeness of human life, with the spiritual quality of life that is unique to man. Just what constitutes this quality of life for a particular patient and the therapeutic pathway to it often is extremely difficult to judge and must lie with the consciousness of the physician.<sup>12(p714)</sup>

Another root of the QOL concept goes back to the 1947 World Health Organization (WHO) definition of health as a “state of complete physical, mental and social well-being, and not merely the absence of disease and infirmity.”<sup>13(p13)</sup> The use of the term “well-being” in this definition of health has contributed significantly to the conceptual confusion about what is health and what is QOL. However, despite much disagreement about whether the WHO definition best describes health or perfect happiness, the majority of methodologists in the health sciences and in the social sciences have followed this definition and adopted a policy of incorporating at least 3 dimensions in any scale or index purporting to

measure health or QOL, namely physical function, mental status, and ability to engage in normative social interactions.<sup>14</sup> In a similar way, Karnofsky outlined as early as 1949 that the evaluation of new chemotherapeutic agents in cancer patients should include not only performance status, length of remission, and prolongation of life, but also the patient’s subjective improvement in terms of mood and attitude; general feelings of well-being; and activity, appetite, and the alleviation of distressing symptoms, such as pain, weakness, and dyspnea.<sup>15</sup> In contemporary terms, these subjective improvement criteria can be recognized as QOL considerations.<sup>16</sup>

The first QOL measure that was named as such is Spitzer’s QL-Index.<sup>17</sup> It was based on the notion that measures of sociopersonal or QOL variables should include physical, social, and emotional function; attitudes to illness; personal features of patients’ daily lives, including family interactions; and the cost of illness.<sup>17</sup> Items concerned activities, self-care, general health, social support, and outlook on life. Untypically, it was designed to be used by physicians. The QL-Index is displayed in **Figure 1**.

At the Portugal Conference on Measuring QOL and Functional Status in Clinical and Epidemiologic Research, Spitzer<sup>14</sup> noted that considerable confusion had emerged because the terms QOL, health, and health status were being used interchangeably:

What is said, what is written and what is done seems to be determined at times by the theme of the conference one attends or the title of the book to which one contributes a chapter.<sup>14(p467)</sup>

Ware,<sup>18</sup> at the same Portugal conference, attributed the increasing popularity of the QOL concept in the health care literature to an increasing comprehensiveness of health measures. Whereas health used to be defined primarily in terms of death and the extent of morbidity (ie, disease), the emerging conceptualization of health encompassed how well people function in everyday life and personal evaluations of well-being. Ware, however, preferred a more limited definition when measuring the health of an individual:

<h2 style="margin: 0;">QUALITY OF LIFE INDEX</h2> <h3 style="margin: 0;">SCORING FORM</h3>		Study No. _____ / _____ Age _____ <input type="checkbox"/> <input type="checkbox"/> Sex M1 F2 (ring appropriate letter) _____ <input type="checkbox"/> Primary Problem or Diagnosis _____ _____ Secondary Problem or Diagnosis, or complication (if appropriate) _____ Scorer's Speciality _____ <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Score each heading 2, 1, or 0 according to your most recent assessment of the patient		
ACTIVITY	During the last week, the patient <ul style="list-style-type: none"> <li>• has been working or studying full-time, or nearly so, in usual occupation; or managing own household; or participating in unpaid or voluntary activities whether retired or not .....2</li> <li>• has been working or studying in usual occupation or managing own household or participating in unpaid or voluntary activities, but requiring major assistance or a significant reduction in hours worked or a sheltered situation or was on sick leave ... 1</li> <li>• has not been working or studying in any capacity and not managing own household.....0</li> </ul>	<input type="checkbox"/>
SCORING FORM	During the last week, the patient <ul style="list-style-type: none"> <li>• has been self-reliant in eating, washing, toileting and dressing; using public transport or driving own car .....2</li> <li>• has been requiring assistance (another person or special equipment) for daily activities and transport but performing light tasks ..... 1</li> <li>• has not been managing personal care nor light tasks and/or not leaving own home or institution at all .....0</li> </ul>	<input type="checkbox"/>
HEALTH	During the last week, the patient <ul style="list-style-type: none"> <li>• has been appearing to feel well or reporting feeling "great" most of the time.....2</li> <li>• has been lacking energy or not feeling entirely "up to par" more than just occasionally .....1</li> <li>• has been feeling very ill or "lousy", seeming weak and washed out most of the time or was unconscious .....0</li> </ul>	<input type="checkbox"/>
SUPPORT	During the last week, the patient <ul style="list-style-type: none"> <li>• the patient has been having good relationships with others and receiving strong support from at least one family member and/or friend .....2</li> <li>• support received or perceived has been limited from family and friends and/or by the patient's condition .....1</li> <li>• support from family and friends occurred infrequently or only when absolutely necessary or patient was unconscious .....0</li> </ul>	<input type="checkbox"/>
OUTLOOK	During the last week, the patient <ul style="list-style-type: none"> <li>• has usually been appearing calm and positive in outlook, accepting and in control of personal circumstances, including surroundings .....2</li> <li>• has sometimes been troubled because not fully in control of personal circumstances or has been having periods of obvious anxiety or depression .....1</li> <li>• has been seriously confused or very frightened or consistently anxious and depressed or unconscious .....0</li> </ul>	<input type="checkbox"/>
QL INDEX TOTAL <input type="checkbox"/> <input type="checkbox"/>		
How confident are you that your scoring of the preceding dimensions is accurate? Please ring the appropriate category.		
Absolutely Confident 1	Very Confident 2	Quite Confident 3
		Not Very Confident 4
		Very Doubtful 5
		Not at all Confident 6
<input type="checkbox"/>		

**Figure 1.** The Spitzer QL-Index. Reprinted, with permission, from Spitzer WO, Dobson AJ, Hall J, et al. Measuring the quality of life of cancer patients. A concise QL-Index for use by physicians. *J Chronic Dis.* 1981 ;34:591. Copyright © 1981 by C.V. Mosby.

The goal of the health care system is to maximize the health component of quality of life, namely health status. Measures of health outcomes should be defined accordingly.<sup>18(p474)</sup>

In the mid-1980s, the term “health-related quality of life” (HRQOL) appeared in titles of published articles for the first time. A paper by Torrance<sup>19</sup> is one of the first. He defined HRQOL as the subset of QOL, relating only to the health domain of that existence; this is similar to the approach advocated by Ware<sup>18</sup> but uses a different term. It is useful to note that some of the most well-known HRQOL measures were never presented as such: The Nottingham Health Profile was presented as a measure of perceived health,<sup>20</sup> the Sickness Impact Profile as a measure of health status,<sup>21</sup> and the SF-36 as a health status survey.<sup>22</sup> At some point, however, it became customary to characterize these as HRQOL measures.<sup>23,24</sup> From that time on, the terms “health,” “perceived health,” “health status,” “HRQOL,” and “QOL” are treated as synonymous by many researchers and clinicians.

In the field of medical rehabilitation, QOL measurement commonly involved health status or was qualified by the term “health-related.”<sup>25</sup> To some, this was a subversion of construct of QOL, bringing it into conformity with the biomedical model.<sup>25</sup> Some suggested an alternative approach, with the view that individuals must be allowed to judge their own experiences. To distinguish it from health status, Fuhrer suggested that QOL could be understood from the individual’s perspective, commonly referred to as subjective QOL or subjective well-being (SWB).<sup>10</sup> Dijkers<sup>26</sup> made a similar distinction between the objective and the subjective approach to QOL measurement. The subjective approach defines QOL as the congruence between aspirations and accomplishments, as perceived by the person involved. Measurement of life satisfaction, happiness, and positive and negative affect fall within this category.<sup>26</sup> According to Dijkers, HRQOL is part of objective QOL and refers to components of QOL that center upon or are directly and indirectly affected by health, disease, disorder, and injury (signs, symptoms, treatment side effects, physical, cognitive, emotional and social functioning, etc) and as such overlaps with the concept of health status.<sup>26</sup>

From the beginning, critics have raised their voices against the uncritical use of the term “quality of life.” Gill and Feinstein<sup>27</sup> reviewed 75 papers with quality of life in the title and found that investigators conceptually defined QOL in only 11 (15%) of the 75 articles, identified the targeted domains in only 35 (47%), and gave reasons for selecting the chosen QOL instruments in only 27 (36%). No article distinguished “overall” QOL from HRQOL.<sup>27</sup> To reverse this situation, many theorists, researchers, organizations, and consensus groups have proposed a definition of QOL or HRQOL. The next section of this article will describe a number of approaches.

### Definitions and Models of QOL

A number of attempts to define QOL have been made, reflecting different approaches to the topic. A nonexhaustive selection is presented in **Table 1**. Most of these definitions refer explicitly to an evaluation by the person involved (“satisfaction”; numbers 1-5, 8). Some specify multiple domains (1, 3, 6, 7), and others refer to a more global judgment (2, 4, 5, 8). One definition (7) is more function-oriented than the others, whereas one most explicitly refers to cultural and societal norms that influence the experience of QOL (5). One definition (3) includes both objective and subjective QOL. Only one definition includes the word “health,” although some more are clearly founded in the HRQOL tradition (3, 7).

As it proved impossible to agree on any definition of QOL, a more practical approach to move the field forward turned out to be to describe aspects of QOL. The distinction between HRQOL and SWB made by Fuhrer et al<sup>10</sup> is one attempt to clarify what QOL should encompass.

According to Aaronson,<sup>16</sup> there are 2 common threads in the structure and content of measures that carry the QOL label. First, such measures tend to reflect a multidimensional conceptual approach. Four broad health dimensions are frequently incorporated:

1. Physical health, ie, somatic sensations, disease symptoms, treatment side effects
2. Mental health, ranging from a positive sense of well-being to nonpathological forms

**Table 1.** Examples of definitions of quality of life in the literature

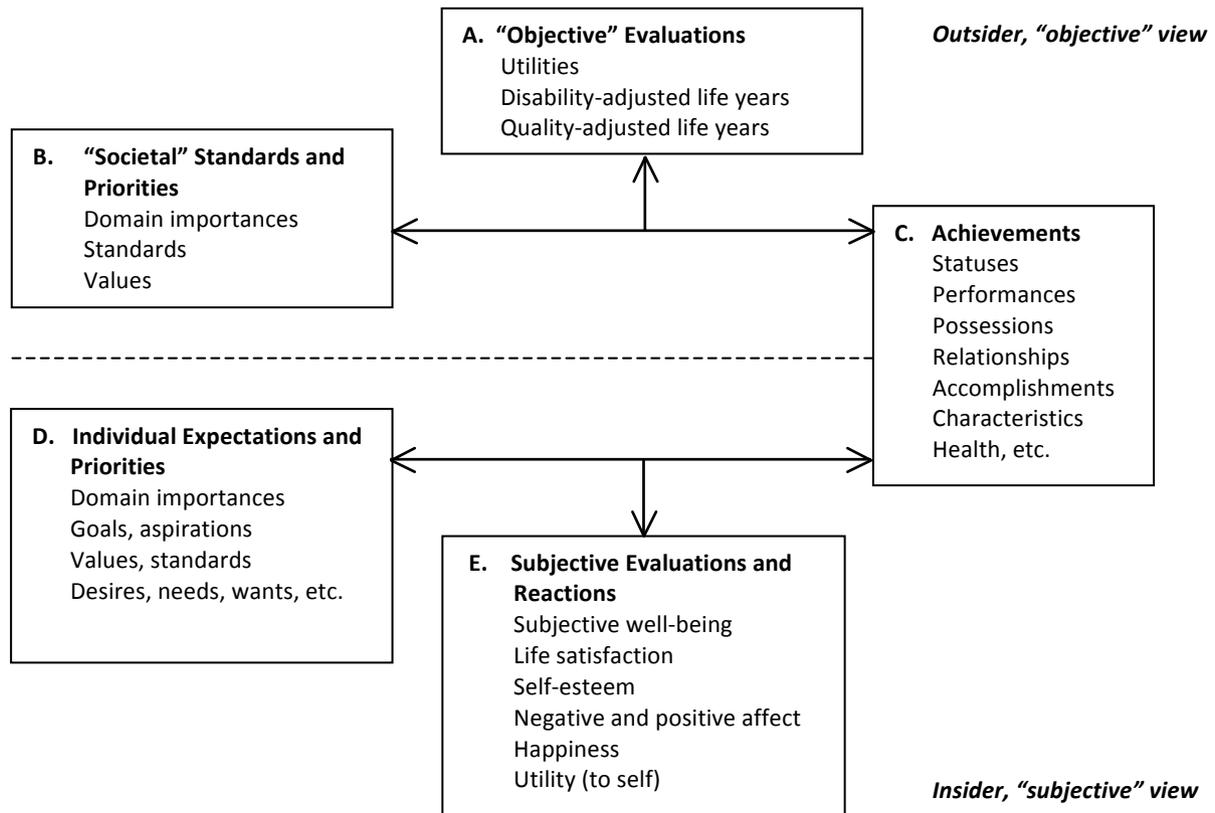
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<ol style="list-style-type: none"> <li>1. The degree of need and satisfaction within the physical, psychological, social, activity, material, and structural area<sup>50</sup></li> <li>2. The subjective evaluation of good and satisfactory character of life as a whole<sup>51</sup></li> <li>3. "...a state of well-being which is a composite of two components: 1) the ability to perform everyday activities which reflects physical psychological, and social well-being and 2) patient satisfaction with levels of functioning and the control of disease and/or treatment related symptoms"<sup>52(p12)</sup></li> <li>4. "...the satisfaction of an individual's values, goals and needs through the actualization of their abilities or lifestyle"<sup>53(p282)</sup></li> <li>5. "...the individuals' perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns"<sup>54(p551)</sup></li> <li>6. "The value assigned to duration of life as modified by impairment, functional status, perception and opportunity influenced by disease, injury, treatment and policy"<sup>55(p22)</sup></li> <li>7. "There is broad agreement that HRQOL is the functional effect of a medical condition and/or its consequent therapy upon a person. HRQOL is thus subjective and multidimensional, encompassing physical and occupational function, psychological state, social interaction and somatic sensation."<sup>56(p12)</sup></li> <li>8. "Subjective quality of life reflects an individual's overall perception of and satisfaction with how things are in their life."<sup>57(p137)</sup></li> <li>9. The overall enjoyment of life<sup>58</sup></li> <li>10. A person or group's perceived physical and mental health over time<sup>59</sup></li> </ol>	<hr/> <ol style="list-style-type: none"> <li>3. Social health, including assessment of both quantitative and qualitative aspects of social contacts and interactions</li> <li>4. Functional health, including both physical functioning in terms of self-care, mobility, and physical activity level and social role functioning in relation to family and work</li> </ol> <p>Beyond these core dimensions, many measures incorporate variables that are specific to a given disease, treatment, or research situation. Thus, for example, QOL evaluations in breast cancer will often include measures of sexuality and body image, studies in rheumatoid arthritis may include expanded assessment of joint mobility and pain, and so forth.<sup>16</sup> The second feature common to most QOL measures is their primary reliance on the subjective judgment of the patients' themselves rather than on ratings provided by physicians, nurses, family members, or other third parties.<sup>16</sup></p> <p>Dijkers<sup>8,28</sup> proposed a comprehensive model of aspects of QOL and its evaluation (<b>Figure 2</b>). The</p>
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main distinction is made among 3 major groups: QOL as subjective well-being (SWB), QOL as achievements, and QOL as utility. Achievements, box C, reflect the current situation of the individual involved. This situation can be evaluated against individual norms and values (box D), resulting in a certain level of SWB (box E), or against societal norms and values (box B), resulting in a utility rating (box A). Utility measures reflect a societal view because their scores are based on valuation of the selected health aspects (mobility, sensory status, symptoms) by laypeople or professionals, instead of by the individual.

Dijkers's model is a great example of a comprehensive QOL model that covers and integrates various approaches to QOL measurement. The main disadvantage of the model might be the lack of incorporation of personal and environmental factors, as described in the International Classification of Functioning, Disability and Health (ICF).<sup>29</sup> Also, the psychological and emotional sequelae, such as coping and adjustment, depression, disability



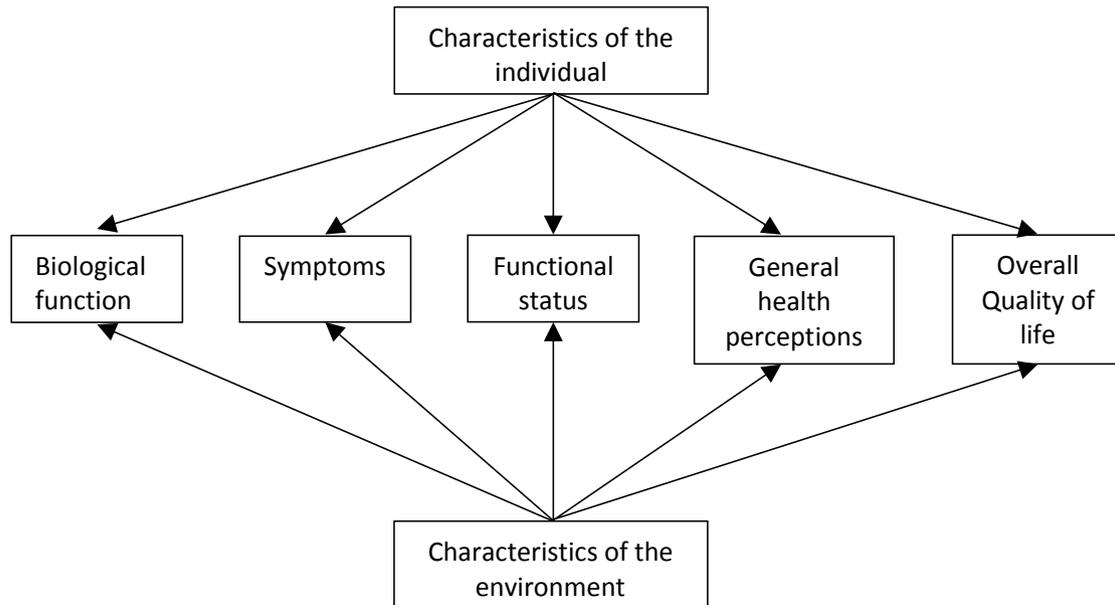
**Figure 2.** Dijkers's model of quality of life and its evaluation. Reprinted, with permission, from Dijkers MP. Quality of life of individuals with spinal cord injury: A review of conceptualization, measurement, and research findings. *J Rehabil Res Dev.* 2005;42:89.

acceptance, and control, might fit in different boxes at the same time. These concepts are part of HRQOL (the mental component), but they reflect subjective QOL at least to some degree.<sup>28</sup>

A popular model of QOL is provided by Wilson and Cleary.<sup>30</sup> This conceptual model links physiological variables, symptom status, functional health, general health perceptions, and overall QOL (**Figure 3**). The arrows in **Figure 3** represent the hypothesized linkages between the dimensions. In the model, the evaluation of physiological variables centers on cells, organs, and organ systems, whereas the assessment of symptom status shifts to the organism as a whole.<sup>30</sup> Functional health has been defined in this model as the ability of an individual to perform and adapt to the environment, measured both objectively

and subjectively over a given period. General health perceptions represent an integration of all the previous health concepts plus others, such as mental health. Overall QOL is described as the discrepancy between a person's expectations or hopes and his or her present experiences. In this model, general health (HRQOL) is a determinant of overall QOL or SWB.

The Wilson and Cleary model is one of the few models that have been tested in empirical research.<sup>31</sup> The main part of the model, without personal and environmental characteristics, was found to fit the data, although this fit could be improved after allowing paths from symptom status to general health perceptions and between symptom status and overall QOL, indicating that symptoms are associated with health and



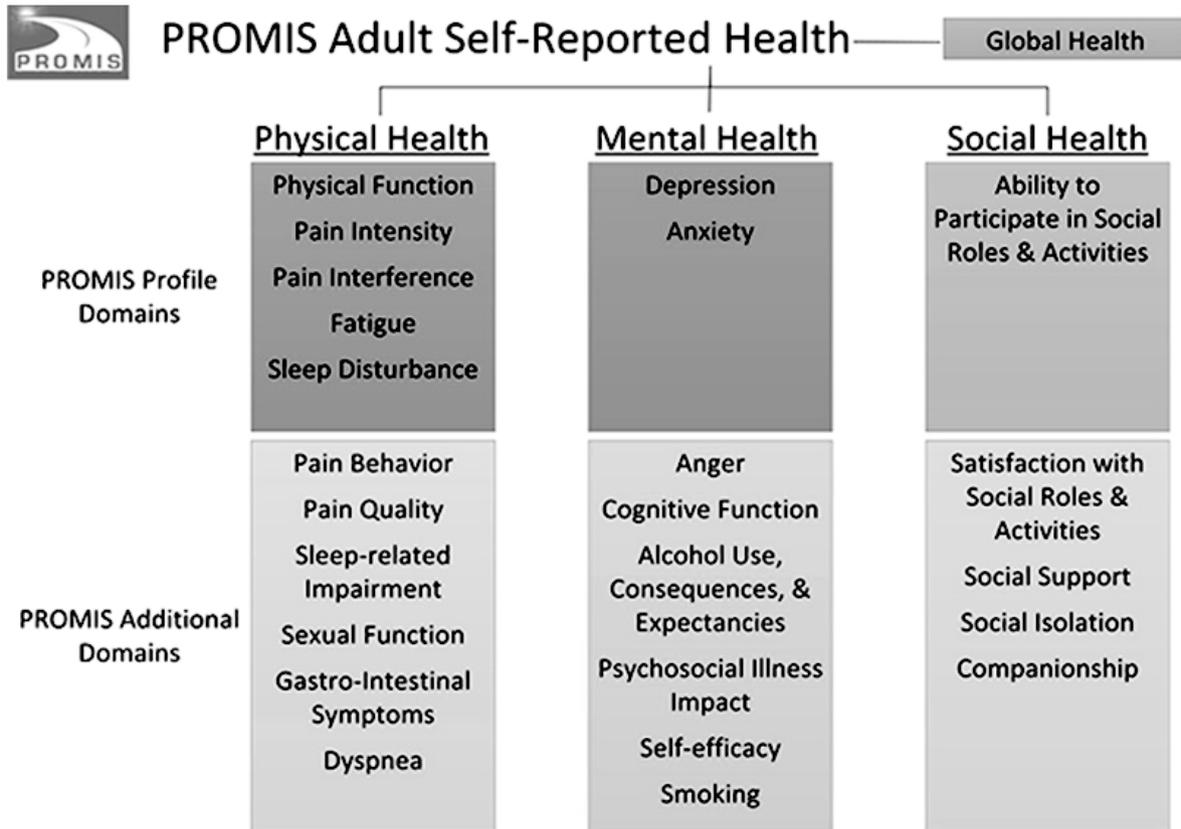
**Figure 3.** The Wilson and Cleary model of quality of life. Reprinted, with permission, from Wilson IB, Cleary PD. Linking clinical variables with health-related quality of life. A conceptual model of patient outcomes. *JAMA*. 1995;273(1):59-65. Copyright © 1995 by the American Medical Association.

QOL independent from their association with functional status.<sup>31</sup>

A model that is strongly founded in the WHO definition of health is the PROMIS conceptual model, displayed in **Figure 4**.<sup>32</sup> The mission of PROMIS is to use measurement science to create a state-of-the-art assessment system for self-reported health. Although the term “quality of life” is not used by PROMIS to characterize the framework, it is clear that a broad operationalization of health as physical, mental, and social health was intended. Within the mental health item banks, PROMIS covers psychosocial illness impact with both a positive and a negative item bank. The positive item bank measures positive psychosocial (emotional and social) outcomes of illness, previously conceptualized in various ways including posttraumatic growth, benefit finding, and meaning making. Positive psychosocial illness impact refers to positive psychosocial outcomes of illness that can occur as a result of confrontation with mortality, such as greater life appreciation, interpersonal relationships, and personal resources (<http://www.nihpromis.org/>

measures/domainframework1). Thereby PROMIS covers SWB as a subset of HRQOL instead of the reverse or as the ultimate outcome.

An original approach to QOL measurement is provided by the developers of the Function-Neutral Health-Related Quality of Life Measure (**Figure 5**).<sup>33</sup> The authors object to the inclusion of functional status items in HRQOL measures. According to them, functional ability was important in the early days of HRQOL measurement, but subsequent conceptualizations of HRQOL have emphasized the importance of distinguishing function from health to define the relationship between these constructs<sup>34</sup> and to examine health outcomes within the context of long-standing functional limitations.<sup>35</sup> According to these authors, the ICF<sup>29</sup> recognizes the possibility that persons can be disabled and healthy and emphasizes the importance of environment on the disabling process. The Function-Neutral Health-Related Quality of Life Measure therefore does not contain any functional status item, and its physical health scale contains items such as energy and pain instead.<sup>33</sup>



03/28/2014

**Figure 4.** PROMIS conceptual framework (<http://.nihpromis.org/measures/domain framework>). Copyright © PROMIS Network 2011. Reprinted with permission, PROMIS Health Organization and PROMIS Cooperative Group.



**Figure 5.** Conceptual framework of the Function-Neutral Health-Related Quality of Life Measure. Reprinted, with permission, from Krahn GL, Horner-Johnson W, Hall TA, et al. Development and psychometric assessment of the function-neutral health-related quality of life measure. *Am J Phys Med Rehabil.* 2014;93(1):60. Copyright © 2014 by Lippincott Williams & Wilkins.

## QOL in SCI Research

Crewe appears to be the first researcher to publish a QOL study in persons with SCI. She used a life satisfaction measure to determine QOL.<sup>36</sup> Another early publication came from Sweden.<sup>37</sup> These authors used a health status measure, the Sickness Impact Profile,<sup>21</sup> to measure overall and physical and psychological functioning, the Mood Adjective Checklist<sup>38</sup> and the Hospital Anxiety and Depression Scale<sup>39</sup> to measure mood disturbances and feelings of anxiety and depression, and a series of self-developed items to measure accessibility of the environment. They also included one item on overall QOL, thereby covering health status or HRQOL and SWB.

Until recently, SWB measures were used more often than HRQOL measures in SCI research. Dijkers reviewed the QOL literature in 1997 and included mainly life satisfaction and happiness measures.<sup>26</sup> He included 22 studies in which results from 18 different samples were reported using a total of 12 different SWB measures.

Tate et al<sup>25</sup> focused on studies using subjective QOL measures in her review of QOL measurement in SCI. These authors described 4 ways in which QOL was conceptualized in the studies they reviewed:

1. As a subjective evaluation of the good characteristics of a person's life
2. As a composite variable referring to an individual's subjective overall satisfaction with life
3. As a multidimensional construct primarily based on a person's subjective appraisal of physical, functional, emotional, and social well-being
4. As the fit between a person's expectations and his/her achievements, as experienced by the person and within a time perspective

The third operationalization refers to HRQOL: Two studies were included in which the SF-36 or the SF-12 were used, despite the focus on subjective QOL.

Tate et al<sup>25</sup> also described their experiences with HRQOL measures. In addition to various measurement issues, they noted one conceptual problem with the use of the term "health" in

the SF-12. Some participants had difficulty interpreting the word "health." As one individual said, "What do you mean by health? I'm healthy and my health doesn't limit me but my spinal cord injury does." There was a substantial difference in the interpretation of whether or not functional limitations resulting from SCI were included in the concept of health.<sup>30</sup> Of all respondents, 21% never included their SCI, 28% sometimes included it, and 51% always interpreted health as including the effects of their SCI.<sup>25</sup>

The developers of the Participation and Quality of Life (PARQoL) Toolkit ([www.parqol.com](http://www.parqol.com)) adopted Dijkers's model of aspects of QOL to categorize the included QOL measures. This was not easy, as many measures were listed in multiple boxes, for example, both in the Achievements box and in the Societal Standards and Priorities box (**Figure 2**). The PARQoL effort is one of the few to discuss the relationship between SHCs due to SCI and QOL.<sup>40</sup> SHCs are prevalent in SCI, hence, it is a challenge to identify a measure that is sensitive to the impact of SCI when it is likely that the individuals are contending with one or more additional SHCs. Also, to assess health condition impact, the outcome measures that are used must be sensitive to the impact of a particular SHC.<sup>40</sup> Both the PARQoL and the Spinal Cord Injury Rehabilitation Evidence (SCIRE) Web sites provide information on a number of outcome measures specific to certain SHCs, such as the Qualiveen tool<sup>41</sup> for the perceived impact of urinary incontinence and the Patient Reported Impact of Spasticity Measure.<sup>42</sup>

The Spinal Cord Rehabilitation Evidence team reviewed QOL measures that are used in SCI, and they followed the objective/subjective distinction proposed by Dijkers.<sup>26</sup> They included 8 objective and 5 subjective QOL instruments.<sup>11</sup> Objective measures included HRQOL measures such as the SF-36 and SHC-specific measures such as the PRISM. Subjective measures included the SWLS and the WHOQOL-BREF.<sup>11</sup> The authors also included a utility measure, the Quality of Well-Being (QWB) scale. The QWB is the only measure included in this review that

provides quality-adjusted life years for health economic analyses, representing the Outsider perspective in Dijkers's model.<sup>28</sup>

Hill et al<sup>11</sup> state that many authors agree that the use of subjective QOL measures is more appropriate than objective QOL measures in individuals with SCI. Objective measures are based on the assumption that all individuals prioritize common life domains and goals and that success and achievement in these domains and goals are directly proportional to happiness and life satisfaction. Such instruments have the potential to miss many aspects of the individual's life.<sup>11</sup> However, this is not a general consensus. HRQOL is frequently measured in many SCI studies. A recent review found no fewer than 174 SCI studies in which the SF-36 or SF-12 was used.<sup>43</sup>

Utility measures, the societal valuation of the QOL of persons with SCI, are rarely used in SCI studies. A review identified 22 articles that used 10 different measures or versions of measures.<sup>44</sup> Eleven papers reported mean utility scores (from 6 different instruments). No studies used preference-based measures in their conventional form, that is, to calculate quality-adjusted life years using patient-level data.<sup>44</sup>

There are numerous instruments for measuring QOL, and there is a wealth of data on QOL in individuals with SCI. However, comparability of QOL results is limited due to the diverging definitions, operationalizations, and measures. These problems are not specific to SCI research; they are also found in the general QOL literature. Specific challenges in SCI research are the distinction many people make between having SCI and being healthy<sup>25</sup> and the major impact SHCs have on HRQOL and SWB in addition to functional limitations.<sup>45</sup>

### How to Move On

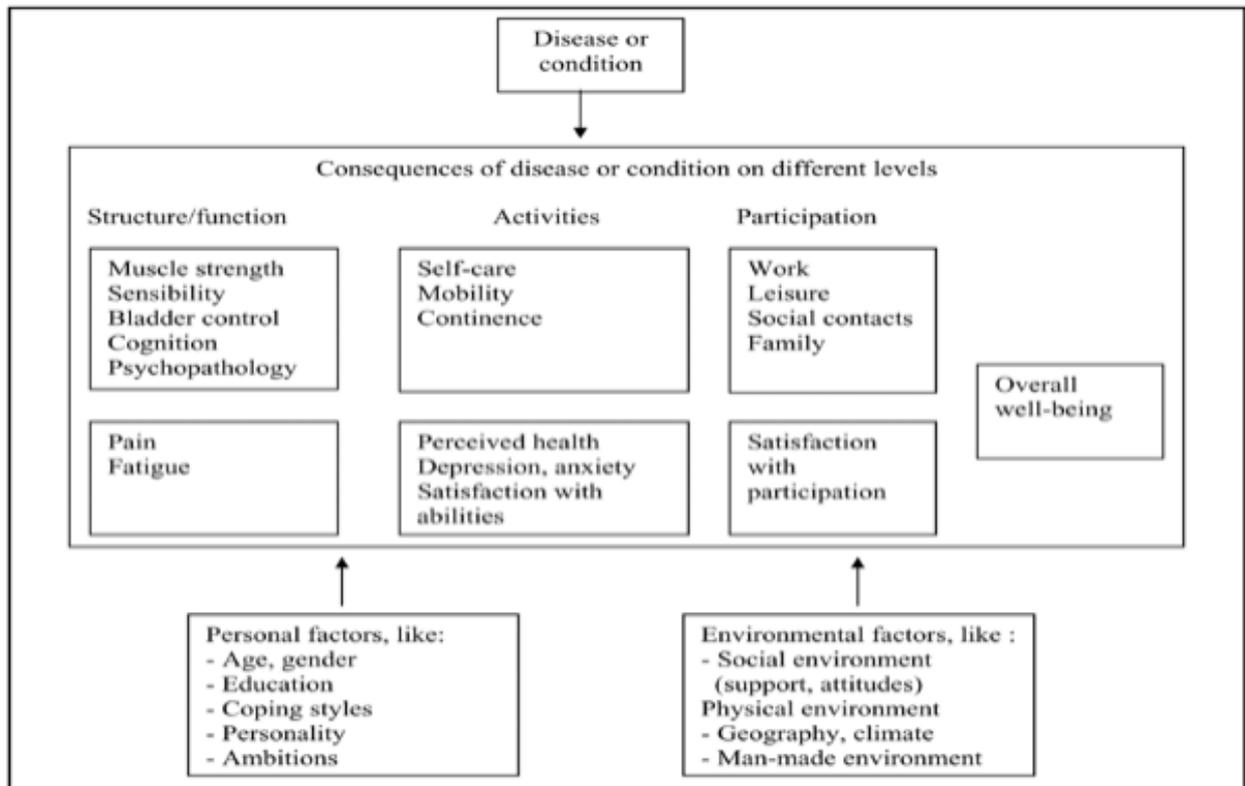
The many definitions and operationalizations of QOL elicit little optimism about the possibility for reaching a consensus among researchers and clinicians. The best researchers can do is to be very clear about (a) the concept, (b) the "what," and (c) the "how." The final part of this article will be dedicated to an exploration of these 3 issues.

### The concept

It would have been a easier if researchers could have agreed long ago to abandon the term "quality of life" completely, or to use the term "quality of life" only to refer to subjective well-being – global judgments of the individual involved, that is, overall subjective QOL, happiness, general well-being, or overall life satisfaction – acknowledging that there are subtle differences between these concepts.<sup>5</sup> Now in excellent papers, we read complicated phrases such as, "understanding physical, psychological and social *well-being factors* that *affect the quality of life* of persons with SCI [italics added]."<sup>243(p128)</sup> Without knowledge of the WHO definition of health and making the assumption that QOL refers to subjective QOL, it is not easy to understand this statement, because well-being as a determinant of QOL seems to make little sense. Such a statement would be easier to understand if it were rephrased as understanding physical, psychological, and social health factors that affect SWB of persons with SCI.

It would also be helpful to clarify whether paralysis, pain, unemployment, and so on are *aspects* of QOL or *determinants* of QOL. It might make sense to study the consequences of SCI on the level of body functions (motor and sensory impairment, SHCs), activities (mobility, self-care), and participation and QOL, as hypothesized in the Wilson and Cleary model (**Figure 3**). This view on QOL is incorporated in a model of rehabilitation outcomes research we published some years ago (**Figure 6**).<sup>9,46</sup> Using this view, it would also not be necessary to develop a function-neutral QOL measure.<sup>33</sup>

In a QOL article, it would be useful to have a definition of QOL that fits the topic of the study or, alternatively, for the term "quality of life" to be used only as an umbrella for any aspect of living with illness or disability. All who use the term "quality of life" should be aware that there are many meanings of the phrase and they should specify what exactly they mean with the label.<sup>47</sup> The reader of a QOL article is advised to not infer any content or focus of the study from the use of this term, but to look for what is actually measured in the study. Even if a definition is provided in the article, it is not



**Figure 6.** A comprehensive model of quality of life. Reprinted, with permission, from Post M, Noreau L. Quality of life after spinal cord injury. *J Neurol Phys Ther.* 2005;29:140. Copyright © 2005 by Lippincott Williams & Wilkins.

certain that the measures the researchers used fit this definition.

### The “what”

Apart from general SWB measures such as the SWLS, QOL measures usually include items on different aspects or domains of QOL. Ware<sup>18</sup> suggested that QOL measures need to include measurement of at least 5 distinct dimensions: physical health, mental health, everyday functioning in social activities, everyday functioning in role activities, and general perceptions of well-being. The aspects or domains that are included (eg, mobility, communication, material or spiritual life) vary strongly between measures. Selection of a measure should therefore be based on the goal of the study and inspection of the contents of promising measures. The model in **Figure 6**

provides a basis for the selection of aspects to study.<sup>9</sup> Few generic HRQOL measures contain items on neuropathic pain or spasticity or other SHCs; so if these are important to measure in an SCI study, additional domain-specific measures have to be included in the protocol.<sup>40</sup>

Measures differ in the way items on specific aspects are grouped into scales or an overall score, and the number of items on a certain aspect determines the weight of that aspect in the scale or total score. It is therefore less useful to make comparisons between total scores of different measures. Results should be reported on a scale level and not on a subtotal or total score level. However, even labels of scales are only rough indicators, and it is by no means guaranteed that one mobility scale is comparable to another mobility scale. The development of the SCI-Functional Index<sup>48</sup> with internally homogenous

item banks for ambulation, basic mobility, hand function, and other aspects of functioning is a good example of this approach. The drawback of course is that it might increase the number of outcome scores in a QOL study to infinite.

### The “how”

An aspect of measures that is neglected too often is the type of rating. The first distinction to be made is between measures of performance and measures of experience. Apart from physical tests, such as a 10-meter walking test, performance is usually measured with questionnaires. Performance can be rated in terms of frequency of behaviors, time, speed or distance, independence, and so on.

Measures of experience are called subjective, because they rely completely on self-report. Assessment of experiences is generally impossible without the individuals involved giving information. Experiences can be rated as perceived difficulty, satisfaction, or importance. The type of rating that is used makes a difference; the

correlation between experienced participation restrictions and satisfaction with participation was not higher than 0.49 in an SCI study.<sup>49</sup>

A special case of rating is the outsider rating used by utility measures, as described previously. This type of measurement is still relatively rare in SCI studies.<sup>44</sup> The principle of an outsider rating<sup>28</sup> contradicts the principle of QOL measurement, that is, the rating by the individual involved should count and not the rating by someone else, either a health professional or the general public.<sup>16</sup>

### Conclusion

Even without consensus on the definition of QOL, substantial gains can be made in the clarity and comparability of QOL research in individuals with SCI.

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